

NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

Embedding Health Equity in a Cluster Randomized Trial of an Advance Care Planning Intervention



Kimberly S. Johnson, MD

Professor of Medicine and Director of the Duke Center
for Research to Advance Healthcare Equity, Duke Health

Housekeeping

- All participants will be muted
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions from chat box and ask them at the end
- Want to continue the discussion? Associated podcast released about 2 weeks after Grand Rounds
- Visit impactcollaboratory.org
- Follow us on Twitter & LinkedIn:

 @IMPACTcollab1

<https://www.linkedin.com/company/65346172>



Learning Objectives

Upon completion of this presentation, you should be able to:

- Describe current gaps and challenges in equitable conduct and reporting of research findings.
- Describe strategies to promote diversity, equity, and inclusion throughout the research process.
- Identify at least one opportunity to embed processes to increase enrollment of underrepresented populations in your work and promote equitable access to your research studies.

Who is in the virtual room?

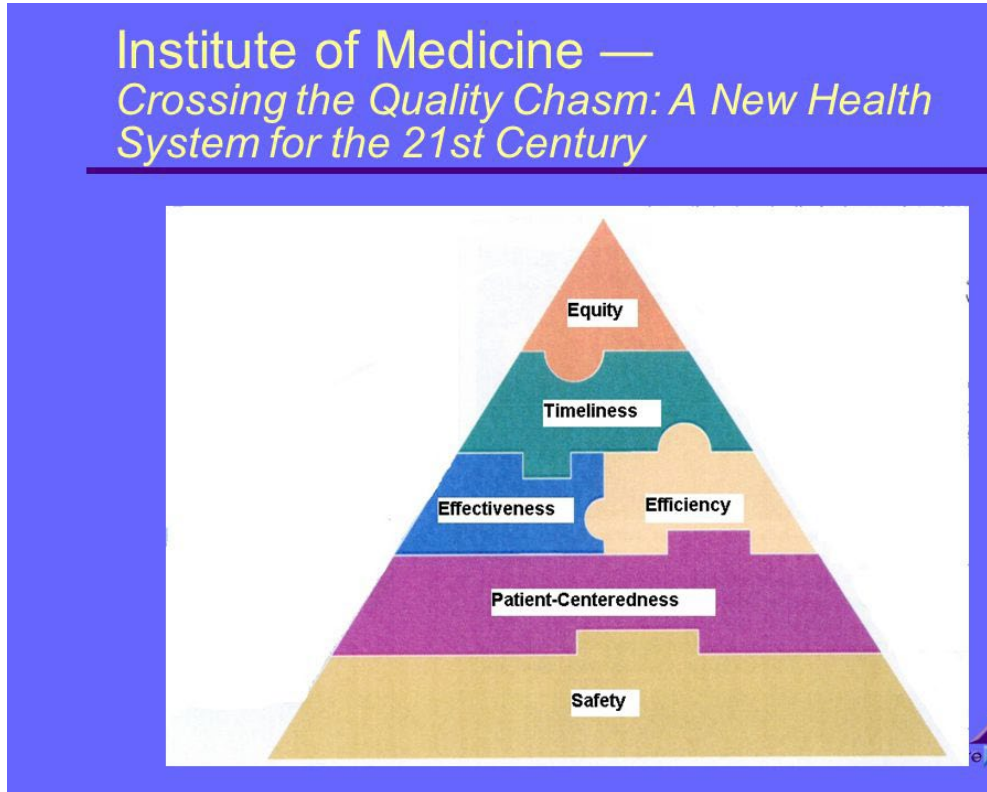
- How many investigators conduct research to address disparities or improve health equity?
- How many investigators conduct research to improve quality of care?

Equity and Quality

- Hard to move needle on either without the other
- How can we improve quality for patients—Black or White, rural or urban, etc.?
- Potential for significant gains in quality improvement for patients with disproportionately poorer outcomes



Equity as a Cross-Cutting Dimension of Quality



Crosscutting Dimensions	Components of Quality Care	Types of Care			
		Preventive Care	Acute Treatment	Chronic Condition Management	
E Q U I T Y	Effectiveness				
	Safety				
	Timeliness				
	Patient/family-centeredness				
	Access				
	Efficiency				
	Care Coordination				
	Health Systems Infrastructure Capabilities				
	V A L U E				

FIGURE S-1 An updated conceptual framework for categorizing health care quality and disparities measurement.

Which aspects of quality do you care about?

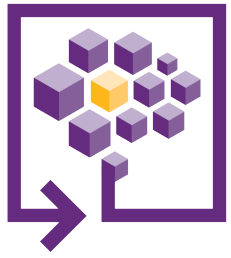
- Communication
- Goal-concordant care
- Patient/family satisfaction with quality of care
- Pain and Symptom Management
- Hospice Use
- Palliative Care
- Disease prevention
- Early Diagnosis
- Symptom Severity
- Care Experience
- Access to Treatment
- Caregiver Burden
- Palliative Care

Which do disparities exist?

- Communication
- Goal-concordant care
- Patient/family satisfaction with quality of care
- Pain and Symptom Management
- Hospice Use
- Palliative Care
- Disease prevention
- Early Diagnosis
- Symptom Severity
- Care Experience
- Access to Treatment
- Caregiver Burden
- Palliative Care

What are opportunities to improve quality?

- Communication
- Goal-concordant care
- Patient/family satisfaction with quality of care
- Pain and Symptom Management
- Hospice Use
- Palliative Care
- Disease prevention
- Early Diagnosis
- Symptom Severity
- Care Experience
- Access to Treatment
- Caregiver Burden
- Palliative Care



NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

We are all disparities investigators!!!

We are the workforce needed to increase research capacity to address disparities and improve health equity.

We have the opportunity to generate evidence that addresses equity.



Gaps and opportunities

Race and Ethnicity in Treatment Trials of AD

Table 1
Main characteristics of the 49 included studies.

	Donepezil	Rivastigmine	Galantamine	Memantine	Total
Studies (n)	18	10	9	12	49
Participants (n)	5,504	4,908	6,493	4,089	21,000
Age (weighted mean \pm SD)	75.8 \pm 5.1	73.2 \pm 2.4	75.1 \pm 3.3	76.2 \pm 4.3	74.8 \pm 4.4
Sex (F,%)	64.5	63.3	64.4	63.9	64.1
Studies reporting race (n)	12	3	5	9	29
Race of participants*					
White (%)	76.4	57.6	92.6	78.2	78.4
Black (%)	1.9	0.4	0.7	0.6	1.0
Hispanic (%)	0.8	0	0.3	14.3	3.4
Asian (%)	19.6	35.0	3.3	0	13.0
Native American (%)	0.02	0	0	0	\approx 0
Missing/unspecified (%)	1.3	7.0	3.1	6.9	4.2
Impact of race on treatment outcomes (n)	–	–	–	–	–

* White or Caucasian or Non-Hispanic white; Black or African American; Asian or Oriental or Asian/Pacific; the “Missing” category includes missing information, and unspecified races.

Race and Ethnicity in Treatment Trials of AD

- 16 US Trials
- 6/16 (37.5) Race or Ethnicity Not Reported
- 5/16 (31.3) White only race group included
- 5/16 (31.3) White and Black race included
 - Mean % of White participants: 91.7%
 - Mean % of Black participants: 3.2%



Why does including a diverse sample and reporting race and ethnicity matter in this context?

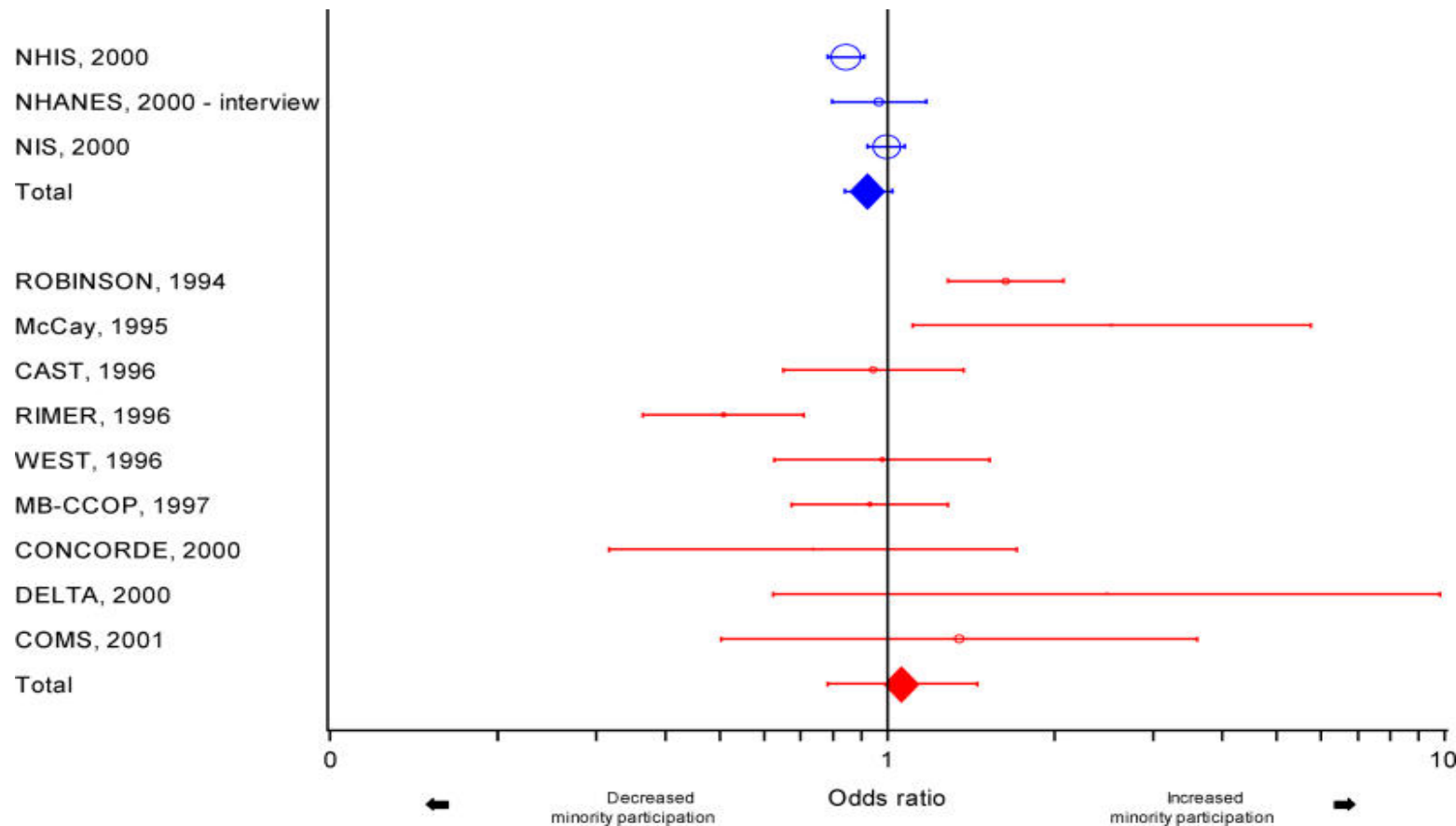
- Baseline variation in:
 - Prevalence of Disease
 - Outcomes we are trying to improve
 - Beliefs and Knowledge
 - Sociodemographic factors
 - Structural Racism
 - Provider approaches and access to care



Why do some racial/ethnic groups participate at lower rates?

- Historical and current relationship between underrepresented populations, health systems and research
- Broader inequities across all “systems” and sectors
- Socio-cultural factors
- Lack of information, awareness, and access
- System barriers

Consent Rates Similar for Black and Non-Hispanic White Participants



In some studies, relatively few racial and ethnic minorities were approached for participation.



REducing Disparities in the QUALity of Palliative Care for Older African Americans through Improved Advance Care Planning (EQUAL ACP)

Kimberly Johnson MD MHS, Principal Investigator
Duke University School of Medicine

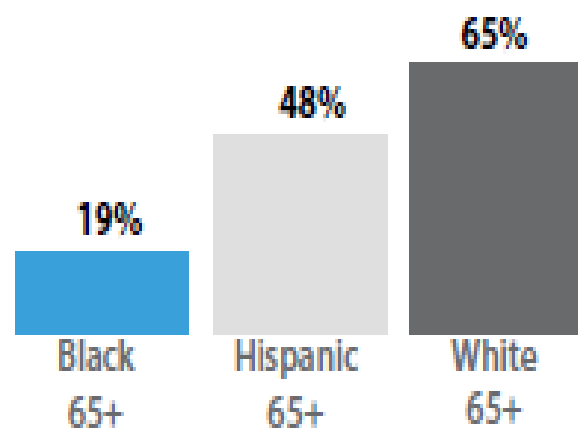
Marie Bakitas PhD, University of Alabama at Birmingham
Deborah Ejem, PhD, University of Alabama at Birmingham
Raegan Durant MD MPH, University of Alabama at Birmingham
Ronit Elk, University of Alabama at Birmingham
Anupama Gangavati, University of Texas, Southwestern
Tammie Quest MD, Emory University
Ramona Rhodes, Central Arkansas Veterans Healthcare System

African Americans have lower rates of ACP

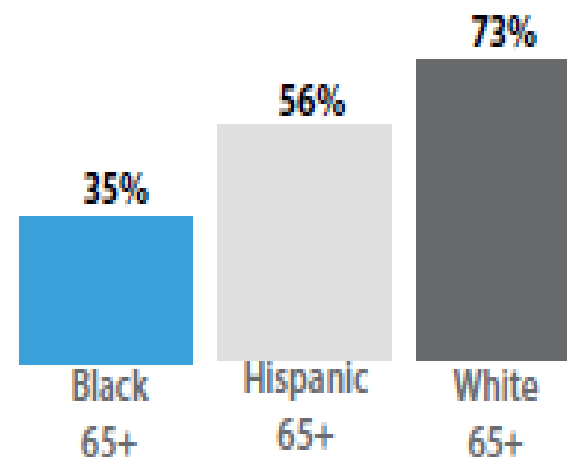
Older Black adults (65+) are less likely than older Whites and older Hispanics to report having written wishes

% with document that...

describes their wishes for medical care if they become seriously ill



names who they want to make decisions about their medical care if they can no longer make them on their own



Informal ACP

Less likely to discuss preferences for care with physicians, family.

Why focus on ACP Interventions?

- Care consistent with preferences
- Satisfaction with communication and quality of care
- Less caregiver depression, anxiety
- Less intensive costly therapies



Disparate outcomes for African American vs White patients

Engagement: Early and Often

- Planning the Study
 - Diverse community partners—CTSA resources
 - African-American patients and caregivers from prior studies
 - Advisory Board
 - Bereaved caregiver and minister, community educator
 - Older African-American with multiple comorbidities and hospitalizations over last year
 - Community Health Coalition—nonprofit providing health education in Durham
 - Triangle Area Agency on Aging
 - Director of Aging with Dignity, CMO of Coalition to Transform Advanced Care
 - **Stakeholder Coinvestigator— Carolina’s Center for Hospice and EOLC**

Views of Community Partners

Theme	Topics and Quotes
Discomfort with Topic and Fear	People are not comfortable or ready to talk about it. People have a fear of dying that leads to procrastination.
Lack of Knowledge	People do not know what an advance directive is.
Spiritual Beliefs	Discussing your wishes may seem like you have no faith.
Trust	People do not trust the medical community due to medical disparities and medical racism.
Documents are not needed	We know what the person would want at EOL from family conversations. We just don't fill out the form.
Relationship with physician	Physicians are always rushing and you don't feel any compassion from the physician.

What do we know about ACP interventions and African Americans?

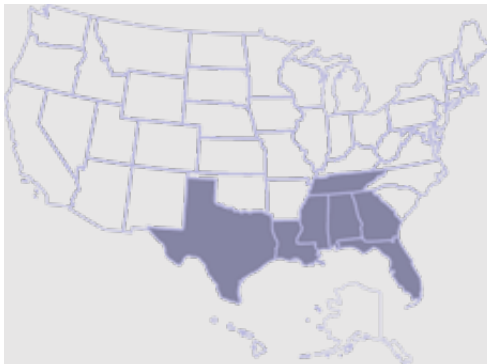
- Studies of ACP interventions not powered to detect differences in racial subgroups
- Studies focused on African Americans small, single disease, short term follow up
- Studies combine “minorities” into one group
- Thinking beyond “document completion”

EQUAL ACP-Research Objectives

- Compare the effectiveness of a two different interventions in increasing rates of advance care planning among older African American and older White patients.
- Determine if the racial concordance between patient and interventionist is associated with rates of advance care planning.
- Among decedents, compare the effectiveness of two different ACP interventions in reducing racial disparities in the quality of EOL care (satisfaction, caregiver satisfaction, goal concordant care, healthcare utilization).
- Describe racial differences in the experience of ACP process, including beliefs, values, and goals which inform individual approaches.

HOW WILL THE STUDY BE CONDUCTED?

Design: Multisite, longitudinal, matched pair, cluster RCT, qualitative interviews



10 CLINICS; 5 STATES
(AL, GA, TX, NC, SC)



800 ADULTS
AGE 65 OR OLDER
with serious illness
(half African-American)



FOLLOWED 1 YEAR
to determine if
they participate in
ACP (write down
or discuss wishes)



THE STUDY
WILL LAST FOR
5 YEARS

EQUAL ACP: Eligibility Criteria

- Inclusion Criteria
 - African-American or White age ≥ 65 with a serious illness
 - English-speaking, residing in noninstitutional setting
 - Cognitively able to participate in facilitated ACP conversations
- Exclusion Criteria
 - residence in nursing home or assisted living facility
 - diagnosis of dementia or unable to consent
 - documented advance care plan (living will, health care proxy, MOST form, provider note) in prior year
 - current or prior use of hospice or non-hospice palliative care except inpatient palliative care consultation

Serious Illness

- (a) EMR review confirming presence of either of the following:
 - cancer (metastatic or hematologic)
 - end-stage renal disease
 - advanced liver disease or cirrhosis
 - COPD or ILD on home oxygen or hospitalized for condition in last year
 - diabetes with heart disease, peripheral vascular disease, renal disease
 - Stage III or IV congestive heart failure
 - ADL disability or two or more unplanned hospitalizations in the past year
 - \geq age 75 with 2 or more comorbidities
- (b) Clinician answers “no” to the surprise question:
 - “Would you be surprised if this person died in the next 12 months?”

HOW WILL EQUAL ACP BE CONDUCTED?

COMPARING 2 WAYS TO INCREASE ACP



VS.



FIVE WISHES FORM

Patient-Driven Approach

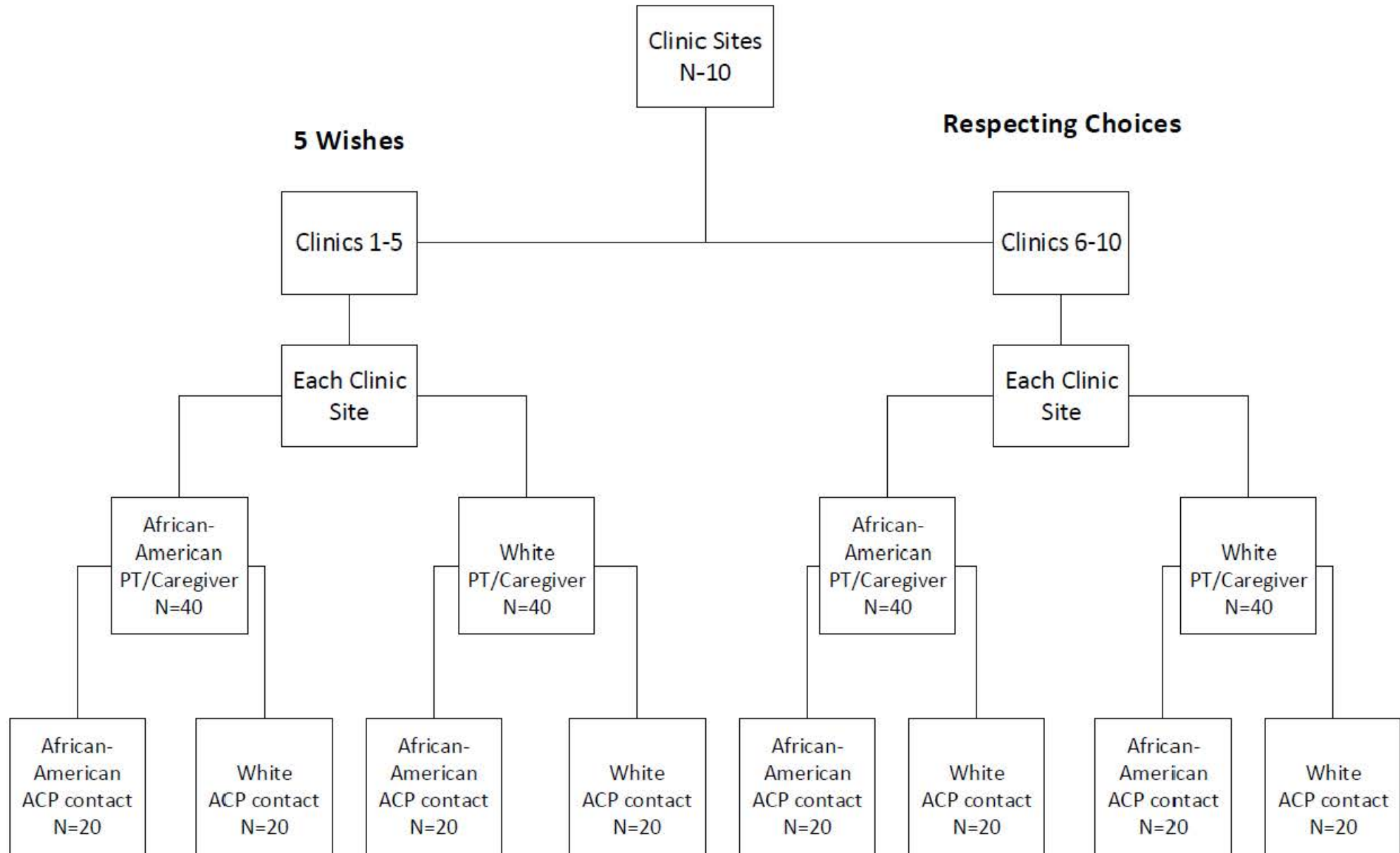
- Patients receive an easy to read form which allows them to discuss/write down their wishes.
- Trained person follows up by phone.

RESPECTING CHOICES

Structured Approach

Specially trained person leads 60 to 90 minute conversation with patients and their caregivers.

Equal ACP Study Design



Engagement in Study Design: Comparators

- Patient-driven self-management approach—Five Wishes
 - most widely used advance directive in America
 - Legal in 42 states and used in other states with AD forms
 - nontechnical language (7-8th grade reading level)
 - “Wishes” for:
 - (1) Person to make medical decisions
 - 2) The kind of medical treatment I want or don’t want
 - (3) How comfortable I want to be
 - (4) How I want people to treat me
 - (5) What I want my loved ones to know

Engagement in Study Design: Comparators

- Structured ACP approach—Respecting Choices
- Training of non-physician facilitators who engage in ACP conversations with patients and caregivers
- First Steps: focuses on identifying cultural, spiritual or personal beliefs that influence treatment preferences, identifying a healthcare agent, and exploring overall goals for medical care

Engagement in Study Design: Interventionists

- Community Health Workers
 - 1/2 Black persons
 - 1/2 White persons

Engagement in Study Design: Primary Outcome

- **Formal and Informal ACP**
 - completion of a formal document
 - discussion with clinician in chart
 - Patient report that he/she asked someone to make decisions and/or discussed preferences with decision-maker

Understanding Variation by Race--Measures

- Education, Financial Well-being, Health Literacy
- Social Support
- Preferences for Decision-making
- Preferences for Serious Illness and EOL Care
- Beliefs about Dying and Discussing Death
- Values informing treatment preferences, Barriers to ACP
- Physician communication
- Trust
- Spirituality
- Dig Deeper—Qualitative interviews, record conversations of interventions



NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

Strategies for getting it done

Study Protocol--Logistics

- Systematic identification of patients—chart review
- Systematic approach to recruitment
 - Training of study staff: **Just Ask**
 - Introductory letters from PCP, brochure, phone calls to invite participation
- Make it easy to participate
 - Meet at clinic, intervention at clinic or home or zoom or phone, all procedures available by phone—consent, survey completion
- Provide compensation for time

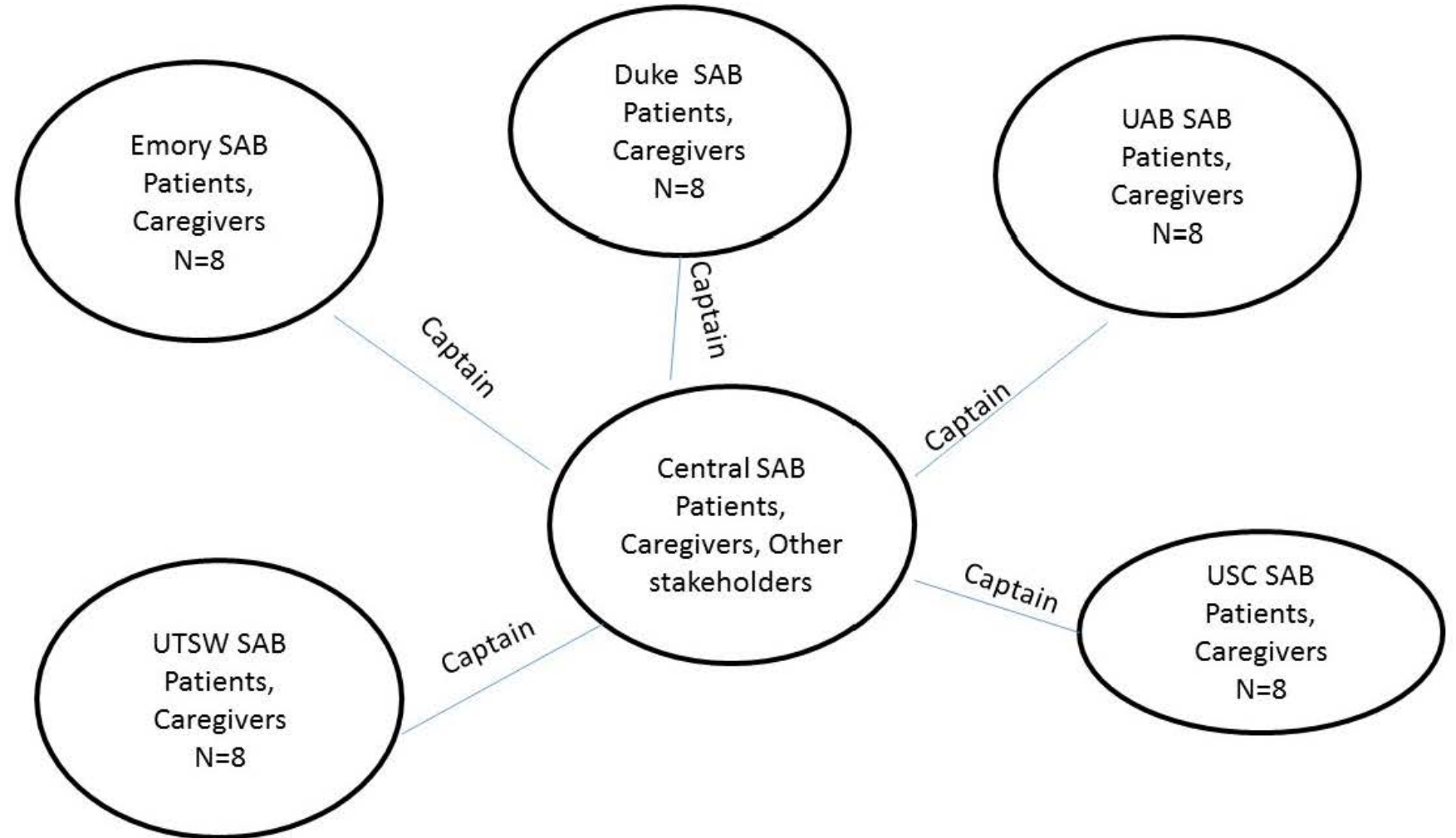
Who is on your team?

- Diversity in research team
 - Race and ethnicity
 - Expertise
 - Patient Recruitment
- Engage community partners, patients, and others with relevant “expertise”
 - From beginning to end—protocol development
 - Measure selection
 - Advertising and recruitment materials
 - Addressing challenges

Stakeholder Engagement

53% are African American.

Patients, caregivers, providers, clergy, advocacy groups

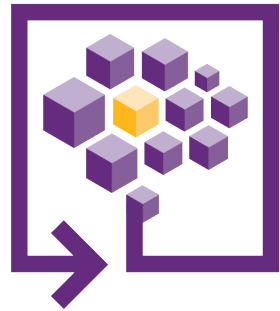


Generalizable Principles and Strategies

- Set goals around recruitment of diverse racial and ethnic groups
- Specify groups using standardized categories: Splitting is better than lumping
- Develop a plan (diverse research staff & training, community engagement & outreach, systematic & targeted recruitment, logistics, sociocultural factors)
- Monitor and make course corrections

Generalizable Principles and Strategies

- Look at variation in findings—Why would “race” matter?
 - Measure and analyze sources of variation (Sdoh, beliefs, preferences, access to care, processes, interventionists, racism)
 - Power adequately to look at differences across populations that experience disparities
 - Consider qualitative interviews
 - What worked or didn’t work?
 - Why?



NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

Questions?

IMPACTcollaboratory.org

 [@IMPACTcollab1](https://twitter.com/IMPACTcollab1)